



Citation for published version:

Cooper, K, Mandy, W, Butler, C & Russell, A 2021, 'The lived experience of gender dysphoria in autistic adults: An interpretative phenomenological analysis', *Autism*. <https://doi.org/10.1177/13623613211039113>

DOI:

[10.1177/13623613211039113](https://doi.org/10.1177/13623613211039113)

Publication date:

2021

Document Version

Peer reviewed version

[Link to publication](#)

FORTHCOMING: Cooper, Kate ; Mandy, William ; Butler, Catherine ; Russell, Ailsa. / The lived experience of gender dysphoria in autistic adults: An interpretative phenomenological analysis. In: *Autism*. 2021. (C) The authors. Reproduced by permission of SAGE Publications.

University of Bath

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

The lived experience of gender dysphoria in autistic adults: An interpretative phenomenological analysis

Kate Cooper^a, William Mandy^b, Catherine Butler^c, and Ailsa Russell^a,

^a Centre for Applied Autism Research, Department of Psychology, University of Bath, BA2 7AY, UK

^b UCL Research Department of Clinical, Educational, and Health Psychology, Gower Street, London, WC1E 6BT, UK

^c Department of Psychology, University of Bath, BA2 7AY, UK

Corresponding author: Kate Cooper, k.cooper@bath.ac.uk, 01225 383947

Declarations of interest: none

Acknowledgements: With thanks to the Spectrum Support Group for helping to develop the research question and methods, and to all the people who took part in the interviews.

Scientific abstract:

Autistic people are more likely to be transgender, which means having a gender identity different to one's sex assigned at birth. Some transgender people experience distress about this incongruence, or gender dysphoria. Few studies have aimed to understand the inner experiences of this group. In this study we used Interpretive Phenomenological Analysis (IPA) to understand the lived experience of gender dysphoria. Twenty-one autistic adults were interviewed about their experience of incongruence between their gender identity and sex assigned at birth, and any associated distress. The interviews were transcribed and analysed using IPA. Participants described significant distress because their bodies did not match their gender identities, their need to understand their identities more broadly, and to manage complex intersecting needs. Participants experienced distress due to living in a world which is not always accepting of gender- and neuro- diversity. Participants described barriers in accessing healthcare for their gender needs. Some participants felt being autistic had facilitated their understanding of their gender identity. Other participants described challenges such as a tension between their need to undergo a physical gender transition versus a need for sameness and routine. In conclusion, there can be both positive experiences and additional challenges for transgender autistic people.

Lay abstract:

Autistic people are more likely to be transgender, which means having a gender identity different to one's sex assigned at birth. Some transgender people experience distress about their gender and sex assigned at birth not matching, or gender dysphoria. Research has focused on finding out why autistic people are more likely to have gender dysphoria, and less on what the experience of gender dysphoria is like for autistic people. We interviewed 21 autistic adults about their experience of incongruence between their gender identity and sex assigned at birth, and any associated distress. We carefully read the transcripts of the interviews, focusing on how participants understood their experiences. We found a range of themes from the interviews. Participants were distressed because their bodies did not match their gender identities. Participants told us they had to work hard to understand themselves and who they were, and to manage having multiple different needs such as mental health needs. It was upsetting for participants to experience discrimination because of being autistic and/or transgender. Some participants said it was more difficult to get transgender healthcare as an autistic person. Some participants thought being autistic had helped them understand their gender identity more than non-autistic people. Other participants found it was challenging to be both autistic and transgender. For example, most participants wanted to change their bodies to match their gender identity, but some participants were nervous about making changes to themselves and their routine due to being autistic. We conclude that autism can in some ways be helpful and other ways contribute to challenges for transgender autistic people.

Introduction

Autistic people are more likely to be transgender, which means having a gender identity different to one's sex assigned at birth (Walsh et al., 2018; van der Miesen, Hurley, Bal & de Vries, 2018). Warrier et al. (2020) found that transgender adults were 3.03 – 6.36 times more likely to be autistic than cisgender people (i.e. people with congruence between gender identities and sex assigned at birth). Other research has explored the relationship between autism and transgender identities, ranging from case-studies of transgender autistic individuals, to measuring autism traits and diagnoses of Autism Spectrum Disorder in transgender people and individuals accessing gender clinics, and rates of transgender identities in autistic individuals across the lifespan (for reviews see: Glidden, Bouman, Jones & Arcelus, 2016; van der Miesen et al., 2016; Øien, Cicchetti & Nordahl-Hansen 2018; Thrower et al., 2020). This association may not be unique to autism; systematic reviews and large-scale studies have indicated that ADHD may also be more common in transgender individuals compared to cisgender individuals (Warrier et al., 2020; Thrower et al., 2020).

Some transgender individuals experience gender dysphoria, which is defined in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) as a significant incongruence between an individual's gender identity and assigned gender leading to distress or impairment. The International Statistical Classification of Diseases and Related Health Problems (11th ed; ICD-11; World Health Organization, 2020) diagnostic criteria have been amended to focus less on distress, broadening the criteria and labelling this as gender incongruence. The criteria for gender incongruence involve a marked and persistent mismatch between an individual's assigned sex and gender, frequently leading to a desire to transition gender. Nonetheless, in the UK, and in line with the Worldwide Professional Association for Transgender Health standards of care (WPATH, 2012), an assessment of gender dysphoria must be made before physical interventions such as gender affirming hormones and surgery can be accessed, and so the experience of distress linked to this incongruence is key to accessing healthcare. Therefore, in this study we focus on experiences of dysphoria linked to gender incongruence. In the UK, individuals experiencing gender dysphoria can access National Health Service gender clinics for psychological support as well as physical treatments including hormone treatment and gender confirmation surgery (Coleman et al., 2012). A systematic review found evidence that in adults with gender dysphoria, undergoing physical interventions improves psychological wellbeing and quality of life, but concluded that higher quality evidence is needed in this field (Nobili, Glazebrook & Arcelus, 2018). Furthermore, the rates of autism of participants in these studies is not known, and so research investigating the well-being of autistic people following physical gender transition is needed.

A recent systematic review and meta-synthesis indicated that a wider range of experiences than those described in DSM-5 gender dysphoria criteria also contribute to distress in transgender adults (Cooper, Russell, Mandy & Butler, 2020). These included being socially isolated due to being transgender, being misgendered, and cognitive and emotional processes linked to experiences of transphobia and harassment. These experiences can be understood in the context of gender minority stress theory (Meyer, 2015; Testa et al., 2015), which refers to experiences of stigma and discrimination due to being transgender which contribute to mental health difficulties (e.g. McLemore, 2018). Given that autistic people also experience minority stress due to their autism identity (Botha & Frost, 2020), it is likely that the experiences of being autistic and being transgender intersect in clinically meaningful ways.

It is crucial to better understand the experience of gender dysphoria in autistic adults, in order to support this potentially vulnerable group. Mental health problems are more common in autistic people (Lai et al., 2019), and in transgender individuals (Dhejne, Van Vlerken, Heylens and Arcelus, 2016). There is emerging evidence that being both transgender and autistic is associated with yet higher rates of mental health problems (George & Stokes, 2018; Murphy, Prentice, Walsh, Catmur & Bird, 2020; Strang et al., 2021a; Strauss et al., 2021). While there have been numerous studies investigating the increased prevalence of transgender identities in autistic people (Glidden et al., 2016), there have been fewer attempts to understand the inner experiences of this group. Strang et al. (2020) call for a move towards research focusing on the lived experience of gender identity in autistic people, and towards an understanding of the intersection of autism and transgender identities.

To date there have been two qualitative studies published on the lived experience of gender diversity and autism. There have been a further two community-based participatory design papers describing the development of a clinical intervention for young autistic people who are transgender (Strang et al., 2020a; Strang et al., 2020b). Coleman-Smith, Smith, Milne & Thompson (2020) investigated the lived experience of gender dysphoria in ten autistic adults in the UK. This study used Grounded Theory and found one overarching theme, named 'conflict versus congruence'. This theme described the participants' experience of conflict between their gender identities and bodies, and also to inter- and intra-personal conflict which was linked to being autistic as well as transgender. Some participants spoke of autism allowing the freedom of expression to embrace their gender identity while others saw autism as a barrier to accessing gender transition (Coleman-Smith et al., 2020). This is in line with research showing that autistic people experience barriers to accessing healthcare more broadly (Mason et al., 2019).

A qualitative study which used framework analysis with 22 transgender autistic youth in the USA found that participants reported a strong need to live in their affirmed gender. Participants emphasised that they were sure their gender identity would persist, and that they experienced significant gender dysphoria, but said that they did not feel the need to conform to gender stereotypes (Strang et al., 2018). Participants felt that being both gender and neurodiverse brought challenges, and that their gender identity had been questioned by others due to their autism. These two important studies demonstrate that autism may affect the phenomenology of gender dysphoria and impact access to gender transition services. It is important to build on this research to provide an evidence base informing health care services provided to this group. To achieve this, researchers need to develop a nuanced understanding of how the experiences of being autistic and experiencing gender dysphoria influence and interact with each other.

In this study we used Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) and aimed to answer the question: what is the phenomenology of gender dysphoria in transgender autistic adults?

Method

Methodological approach

IPA is a qualitative research method which focuses on a specific phenomenon, such as gender dysphoria, and aims to distil the essence of this experience. IPA emphasises the particular, individual lived experiences of participants, and focuses on how each individual participant understands and makes sense of their experiences of a particular phenomenon (Smith, Flowers & Larkin, 2009). This approach acknowledges that the researcher plays an active role in forming an understanding of the participants' experiences, i.e. the researcher will bring their own experiences and expertise to the analysis, and this must be reflected upon by keeping a reflexive attitude and maintaining a keen awareness of the role any researcher biases and preconceptions within the analytic process. IPA has been identified as an important tool in autism research due to its focus on the lived experience and meaning to autistic individuals (Macleod, 2019; Howard, Katsos & Gibson, 2019), and in this study we aimed to stay close to the meaning-making of the individual in order to offer insights into participant experiences, while remaining aware of our identities as non-autistic researchers and clinicians. IPA achieves this through careful analysis of themes in each individual transcript, before moving on to develop themes in the next transcript. This process continues until each individual set of themes has been collated, and only at this point are themes developed across the dataset. See the analysis section for further details of the analytic process.

Participants

We recruited 21 adults who had a clinical diagnosis of Autism Spectrum Disorder. We verified participant autism diagnoses by viewing individual diagnostic reports confirming receipt of an autism diagnosis from a qualified health professional. All participants identified as transgender and/or non-binary and had experienced distress in relation to the incongruence between their gender identity and sex assigned at birth, such that they had discussed their gender experiences with a health professional. Participants therefore may or may not have met DSM 5 criteria for Gender Dysphoria. This was to ensure that a range of autistic experiences of distress linked to gender incongruence were included. The sample was relatively homogenous, in that all participants had an autism diagnosis and experience of gender dysphoria. A larger number of participants were invited to take part to ensure a range of gender identities, ages, stages of transition and geographical location in participants, following advice from the patient and public involvement group who were all autistic transgender adults.

Participants were recruited from National Health Service (NHS) adult autism services (n=10), NHS gender clinics (n=3), and through community groups (n=8) including transgender and autism support groups. Some of the community group sample invited other group members, otherwise known as snowball sampling. All participants who identified as male were assigned female at birth (AFAB), all participants who identified as female were assigned male at birth (AMAB), and of those who identified as non-binary/genderqueer, five were AFAB and one was AMAB. Of those with complete data, 7 (44%) requested support for gender dysphoria and then received an autism diagnosis, and 9 (56%) had an autism diagnosis before requesting support for gender dysphoria¹. See table 1 for a summary of participant characteristics.

Procedure

We received ethical approval for the study from the Health Research Authority (19/NE/0265). In the NHS context, clinicians within each recruitment site spoke to potentially eligible participants about the research project during routine clinical appointments. This clinician assessed participant eligibility for the study, including checking for a confirmed autism diagnosis and for experiences of gender dysphoria, before gaining consent from the potential participant to pass on their contact details to the research team. Participants who were recruited via other members of community groups made direct contact with the study team. The research team assessed community group participants for their eligibility to participate, including confirmation of autism

¹ Five participants were not able to remember either their age of autism diagnosis or of seeking support for gender dysphoria leading to the missing data.

diagnosis by clinic letter from a qualified medical professional, before inviting eligible participants to take part. Participants were invited to meet with a researcher either in-person or online to give fully-informed consent. After consenting, participants completed a demographic questionnaire which collected information about participant age, gender identity, current sexual orientation (using pre-specified options as well as the option for open responses), and journey through the health service for support around both autism and gender dysphoria (see Table 1).

Next, participants were interviewed by the first author about their experience of distress linked to gender incongruence and of seeking help for this in the NHS. Interviews took place between December 2019 and October 2020 and lasted an average of 66 minutes (range 39-104 minutes). The topic guide covered the following areas: earliest experiences of gender dysphoria; experience of being autistic and having gender dysphoria; interaction of gender dysphoria, autism and mental health; seeking help for gender dysphoria; autism adaptations in services. In line with the IPA methodology, open questions were used as much as possible. However, some participants needed autism adaptations to be able to fully respond to questions, including writing down responses (n=3), having someone else in the room to support them during the interview (n=1), and for all participants the interviewer used a flexible and adapted interview style including closed prompt questions. All of the interviews resulted in data that was useful to answer the research question, although some interviews provided a richer dataset than others. Some participants were able and willing to express their lived experience of gender dysphoria in detail, readily accessing their experiences and providing rich descriptions of these, while others took more prompting and were less able to describe their feelings; however this formed part of the analysis in itself.

Interviews were audio recorded using a digital recorder and the audio recording was sent to a professional transcription company and transcribed using an intelligent verbatim method. Participants were reimbursed with a £25 shopping voucher and sent a debrief form following participation.

Table 1. Participant demographic characteristics

Gender	n	%	
Male	7	33%	
Female	8	38%	
Non-binary/Genderqueer	6	29%	
Sex assigned at birth			
Male	9	43%	
Female	12	57%	
Sexuality			
Lesbian or gay	10	47%	
Bisexual	3	14%	
Asexual	4	19%	
Other	4	19%	
Ethnicity			
White British	20	95%	
Mixed	1	5%	
Gender transition undertaken	n		
Process not started*	4	19%	
On gender identity clinic waitlist	4	19%	
Assessment at Gender Identity Clinic	1	5%	
Hormones prescribed	4	19%	
Surgery – ongoing	6	29%	
Physical transition complete	2	10%	
	Mean	SD	Range
Age	29.1	11.5	18-51
Age realised trans	10.2	5.1	0-19
Age when sought help from a professional for gender dysphoria	22.2	8.0	16-47
Age of autism diagnosis	22.5	13.6	3-51

Analysis

Analysis followed the procedure outlined by Smith et al. (2009), with in-depth noting or coding of each individual transcript focused on capturing descriptive, linguistic and conceptual aspects of the data, followed by the development of themes capturing the most important aspects of the individual's experience of gender dysphoria. Themes were developed using processes of grouping together related themes, themes with oppositional relationships, those which shed light on contextual elements, and themes which shared a similar function within the transcript. Once each transcript had been analysed in this way, themes were developed for the whole dataset using similar strategies. Due to the relatively large sample-size for an IPA study, the number of participants for whom each theme was relevant was taken into account (Smith et al., 2009). Where more than half of the participants ($n \geq 10$) had experienced a theme, it was categorised as recurrent and considered for the final analysis. Quotes were extracted and presented in the results when they distilled the essence of a theme, and participant numbers are presented with each quote.

To ensure the credibility of the analysis, the authors discussed their positionality and prior assumptions about the topic before and throughout data collection. The first author kept a reflexive diary during the research process, as well as attending an IPA peer supervision group with other IPA researchers. The analysis was critically evaluated in both the IPA group, in supervision and with the patient and public involvement group to ensure that the analysis was credible and grounded in the transcripts and participants' reported experience.

Community Involvement

A group of transgender autistic adults (n=6) were consulted and formed a patient and public involvement group for the research project. These individuals were identified through an NHS run peer support group for autistic transgender adults, and invited to contribute to the research by giving their opinions on the suggested research question and methods. As well as helping to develop the research question, they also helped to ensure study materials were adapted for autistic adults, reviewing the information sheet and topic guide for the interview. Finally, they were presented the final analysis and theme names, and commented on how the theme names and descriptions could be made accessible to the autistic community.

Results

We present here the themes that were endorsed by at least half of participants (see table 2). In the last paragraph of the results, we present themes which were endorsed by fewer participants but which are relevant to the research question.

1. *Making sense of distress and finding my identities*

The first superordinate theme describes the discomfort and distress that all participants experienced, and had three subthemes. These experiences of discomfort were experienced in participants' bodies and in their sense of self; linked to their multiple identities and life experiences.

a) Experiencing and describing body distress referred to the distress participants felt because of having a body which did not match their gender identity, and all participants described this distress to some extent, though many struggled to clearly articulate it.

Participants spoke of a wide range of negative emotional responses to their bodies including depression, anxiety, anger, and disgust, with some participants referencing dissociation from their bodies. Participant 6 described this experience: "I was resigned to the fact that I'm stuck being a girl and it was quite depressing really ...I felt fairly numb, yes, numb and empty, and just really not connected with my body at all. And then I think I used to feel physically awkward an awful lot of the time and I was always really tense. I could never relax in my body and that in itself would bring its

own discomfort.” A non-binary participant described experiencing “an estrangement” from their body; later describing how “I still feel at my most comfortable and at my best when I have broader shoulders, when I have more body muscle ... where there is more of an androgynous, strong shape to me. I still have to go to some effort to hide if I want other people to treat me a certain way, which is tedious, but I am more comfortable in my skin” (15). Both quotes demonstrate the sense of distress in and detachment from a body which does not align with the individual’s identity. Some participants described puberty as being particularly distressing as their body developed in an unwanted way. For example, a trans male participant described being surprised by puberty as his body developed in an unwanted direction; “I kind of almost grew up like a boy, really, and then puberty happened and it was very distressing, like almost in my brain I wasn’t expecting it to happen” (2).

For many participants these experiences of embodied distress were difficult to articulate verbally. For example, participant 22 said “I may over-estimate or under-estimate” gender dysphoria, and participant 2 stated “It’s just... it’s hard to explain. It’s really hard to explain. I find it hard identifying which emotion I’m feeling. Everything just feels like stress – everything”. When asked to give a description of dysphoria, participant 8 said “Sorry, I don’t know many synonyms for it. Just that thing.” Some participants used concrete, behavioural markers when asked to describe their experience of gender related distress: “...it’s quite unpleasant. There were situations where I was going to cause harm to my family”(23) while other participants described their gender dysphoria in more abstract terms: “I’m sort of nowhere. Sort of disappeared...I don’t know. It makes me feel sad”(5), showing both the distress at not feeling connected to her body, and challenges in communicating this bodily experience.

b) The *making sense of who I am* sub-theme described the importance most participants placed on understanding their identities, and the sense of unease when they did not have this understanding. This lack of a clear sense of identity led to feelings of discomfort and frustration linked to the person’s broader sense of self, going beyond the bodily experiences of the first subordinate theme.

Most participants spent significant time trying to understand themselves. This was not just centred on gender identity, but also autism identity: “I was only diagnosed as autistic two years ago and that made me really re-evaluate an awful lot of stuff because suddenly instead of being awkward and difficult and not making sense it was actually this makes sense.”(16). Participant 13 felt a pressure to find a gender label and wondered “Am I female? Am I like, am I another thing?... I felt I

had to fully label myself and fully figure out why it was. I was really, really low. It was like – it’s hard to explain, but it’s the lowest I’ve ever felt.”

Some participants described experiencing feelings of discomfort that they needed an explanation for and realising that they were both transgender and autistic was hugely important in gaining such an understanding. For example, participant 19 said “It’s been such a relief to accept that there is something different about me and just try and do things in different a way that works for me”. These realisations were experienced as comforting and this allowed new strategies to be implemented to alleviate distress, such as participant 17 who stopped masking autism after a diagnosis: “Then after having a [autism] diagnosis a lot more of my experiences have come to light again and there’s things that I do actually make me really uncomfortable or things that really don’t suit me that I have edited to ignore a long time ago”. While some participants described the utility of labels and diagnoses for understanding the self, a few used different labels before settling on a transgender identity: “Yeah, I tried, and then I went through a phase, ‘Well, if I can’t be a boy, then I’ll just be a butch lesbian’”(2).

c) The *intersecting and competing needs* subordinate theme described the multiple and overlapping difficulties that most participants experienced which sometimes required competing solutions. These complex and multifaceted experiences of distress contributed to feelings of being uncomfortable in oneself. Some participants described these multiple needs as amplifying dysphoria, such as participant 17: “I think how intensely I process it [dysphoria] is autism related”, others felt they were entangled and could not be separated, while others conceptualised these multiple struggles as separate to their gender dysphoria.

Many participants described multiple challenges that they faced which caused significant psychological distress. These challenges including mental health needs, traumatic experiences, and autism-specific difficulties such as being overwhelmed by sensory experiences, and this contributed to distress, such as for participant 6: “I was just completely lost really....there was the gender stuff going on, but there was an awful lot else going on as well...I was really depressed, anxious, isolated, struggling massively socially and I had OCD”.

Many participants described a clash between their autism and gender needs, causing additional distress. Some participants described “sensory dysphoria” (1), which were experiences of distress in their bodies linked to sensory experiences including wearing uncomfortable fabrics and shapes associated with girls’ clothes, and with the sensory challenges of puberty including periods, such as dealing with the smell of blood, and growing facial hair. Many participants reported finding change stressful, alongside a strong need to undertake a social and/or physical gender transition,

and that this caused tension. Participant 6 said “I think because of the fear of changes happening – I really wanted to be in control as much as I could and I asked to have [testosterone] gel instead of injections because...I could just not apply it”. Some participants expressed a desire for their transition to be precise and predictable, such as participant 16 who wished for “nice little tick boxes” for transition and another participant described the uncertainty of the transition process leading to “repetitively kind of winding yourself more up” (2).

Some participants felt a need to be certain about their gender, and that reaching a sense of certainty about their gender identity and expression brought a sense of relief. Concrete thinking linked to autism made it harder for some participants to understand their gender, such as a non-binary participant 19 who described their previous thought process “I hate trying to be a girl but I have to try and force myself to be a man because there’s only two options” and another non-binary participant 20 who said “I don’t really want a body at all because it would never be exactly in between.” This need for gender to be ‘just so’ led to additional experiences of distress.

While the intersecting needs at times contributed to distress, other participants felt that autism had helped with understanding their gender such as participant 22 who felt that autistic people are “more in-tune with their gender” because “we see the world differently”, referring to the idea that being autistic allows one to step outside of societal norms and follow one’s own path.

2. Mismatch between needs as an autistic trans person and society

The next superordinate theme was ‘mismatch between needs as an autistic trans person and society’, which had three sub-themes; doing gender; struggle of being different; battle for support. This theme centred on participant experiences of living in their bodies, gender identities and with their autism features within the social world which is not always accepting of social and gender differences. Most participants therefore had needs which were not easily met in society, needing to come to understand themselves through others who were not always accepting of their differences. It was important that their gender identity and autism identity was affirmed by others, and that they were able to undergo a gender transition despite the barriers they experienced.

a) Gender as social behaviour was the first subordinate theme and centred on the participants’ experience of their gender in the social world. Individuals often experienced their gender identity through the eyes of others, which meant learning how other people thought about gender, considering how their own experience fit with these gender norms, and trying to ensure that their individual gender expression would mean that others did not mischaracterise their gender i.e., misgender them.

Some participants felt that gender was one of many social expectations which did not make sense to them, through being unaware of gender as a concept; “I just didn’t notice that gender was a thing” (18), or being confused by it; “gender was just another one of those things where it seemed like everybody else had a bunch of ideas about how the world was meant to work, it didn’t really seem to make a lot of sense to me”(15). Participant 20 explained how they felt this linked to their autism identity: “Being autistic is like everybody else has got the rulebook and you didn’t, so you can understand why gender would come into it because that was in the rulebook you do not get.” Other participants were aware of and felt comfortable in their non-conformity: “I have never tried to fit in with people, or very rarely. So whilst now my gender presentation is very stereotypically male, there are some things that I do are intentionally more feminine, but I don’t care” (12).

A number of participants stated their rejection of gender norms, while many participants also felt a pull towards stereotypical gender expression. For example, a trans woman stated “basically more or less all my interests were very feminine”(8), showing an awareness that she conformed to gender norms in her interests. Some participants felt repelled by their assigned gender such as a trans woman (23): “I find men real tiresome you know is the real answer...I can’t relate to them at all”. Participants described feeling oppressed by gender norms which did not apply to them, such as participant 22 who felt “if they [other people] try and force gender roles on me I’m not considering them as a person”. Some participants noted feeling affected by gender stereotypes linked to autism: “people who see me as female may not necessarily pick up on my autistic traits as much” (3), referring to the way in which autistic traits can be perceived as being stereotypically male.

Some participants described feeling a range of negative emotions when misgendered: “It was quite traumatic I think. Really painful and just really frustrating that they weren’t seeing what I wanted” (6). For some participants, it could be difficult to work out what others thought about their gender and reaching this understanding took much reflection “I’d get very aware of how I imagined other people were perceiving me, to the point where I’d almost lose myself because I’m imagining being in their perceptive so much” (5).

b) Struggle of being different described the challenges faced by autistic people living in a world which is cisnormative, i.e., expects gender identity to align with sex assigned at birth, and where the differences associated with autism and being transgender can be perceived negatively. Participants struggled against this, sometimes experiencing a desire to fit in to mitigate these negative social experiences, which could be challenging given their differences in gender and social expression.

Many participants described periods of their lives in which they were ostracised and socially isolated due to their identities, such as participant 3: “after I came out I was temporarily homeless because of the situation with my family not exactly accepting or being supportive”. Most participants described experiences of being bullied, othered and socially isolated. Some participants described having difficulties in social situations both as a result of autism and their different gender expression, as described by participant 17: “I think that both of those things [gender and autism] affected how I acted in school and how I felt....I was very tense and very quiet which is not my nature”. A number of participants described autism as being the main cause of social difficulties: “being autistic, people were too preoccupied with that to think about my gender so I never really faced any problems regarding that”(5).

Resulting from these negative experiences, some participants referred to a sense of shame, such as participant 16: “You feel that you’re not very good at this, you’re kind of failing as a person that you just don’t fit anywhere and you just want to retreat”. Some participants spent significant time worrying about how they were perceived by others, such as participant 13: “it’s like the feeling that people are watching me and judging my every move that I make”, while some participants said that they did not worry what others thought of them. Some participants described attempts to blend in and conform to norms around gender and social behaviour, such as participant 2: “Like trying to be what people wanted me to be, depending on the situation, so I never felt like I could truly be myself around anyone, really. I was just being what I had to be to get by. It’s hard work.”

c) The *battle for support* subordinate theme summarised the struggle by almost all participants to be acknowledged in their identities by people in positions of power, primarily professionals in health, education and social care settings. This theme also refers to most participants’ desire to communicate about gender and to undergo a transition, but that features of autism could create barriers to this.

The positions of authority held by clinicians made their affirmation of the person’s identity (as both trans and autistic) hold meaning and power. Participant 10 said “the first appointment I ever did go to was a complete disaster and I don’t think the doctor even believed me. After that I didn’t really go back for a long time”, demonstrating the power of a clinician’s initial response to a request for support around gender dysphoria, and that the clinician’s affirmation of this participant’s experience was needed to continue to get support. Sometimes, interactions at a gender clinic, or with mental health professionals, were described in terms of a battle to get the support the individual wanted. Participant 6 described arriving at GP and gender clinic appointments “armed” (6) with the necessary information to ensure they got a referral or the support they requested. Many

participants spoke of significant barriers to accessing a gender clinic due to their autism. Participant 20 had been unable to access a gender clinic due to dependence on unsupportive family members to attend medical appointments: “I don’t see any professional on my own, so getting a referral would be near impossible”.

Where participants did access a gender clinic, they did not always feel that their autism was considered, and participant 3 felt she “had to appear as neurotypical as possible” to gender clinicians. Others felt that adaptations were made: “once I had a set clinician that I saw every time, it got a lot better” (2). Many participants spoke about communication with professionals being challenging, and participant 18 said of their gender clinic assessment: “a lot of their questions were really open-ended and I never really seemed to understand what they were actually asking”. Participant 7 experienced helpful communication adaptations: “giving us, I wouldn’t say a prompt but did you feel like this, or did you feel this?”. Participant 16 described difficulties with the uncertainty of processes around attending gender clinics; “It was very difficult because there’s no set rules especially with transitioning there’s no kind of checklist well you do this and then you do this ... It would be far easier if there was nice little tick boxes and a list with a timescale.” Participant 2 struggled with the physical environment at the gender clinic: “they had these awful, bright lights that buzz, and then you’re in the room with the clinician and they’ve got their computer on so that’s humming away, and then you’re got the clock ticking and then the temperature’s always way, way too hot and it’s just...bombard you with all the sensory stuff”.

Additional themes

Themes which were endorsed by less than half the participants, but were of relevance to the research question, included that five participants described their vulnerability to abuse by others, with two specifically linking this vulnerability to being both transgender and autistic. For example, participant 1 described how before making any social transition, he thought of himself as a man, and did not consider that others would not see him that way, leaving him vulnerable to abuse: “this guy attacked me and I was in a very vulnerable place ‘cause, again, I had no idea, I just saw myself as male”. Two participants felt that being autistic meant that they spent more time researching gender identity, with participant 12 worrying that gender was a special interest, before concluding that it was not: “At first, I was slightly concerned that, ‘Oh, what if gender is just a new special interest?’ But it went on for so long, way beyond the researching and stuff that I was, ‘No, this is...’ “. Two non-binary participants felt that autism was a more central identity than gender: “I grew up autistic and spectrum is inseparable from my lived experience of any other characteristic.” (15)

Table 2. Themes and quotes describing the autistic experience of gender dysphoria

Superordinate theme	Subordinate theme	Supporting quote	Number of participants included in theme
1. Making sense of distress and finding my identities	a) Experiencing and describing body distress	19: "I am forever stuck in a body that I am not going to like and there's no way I can go back to how I was before puberty"	21
	b) Making sense of who I am	9: "My identity is something that I've had to figure out and it was really difficult."	17
	c) Intersecting and competing needs	1: "I've been told I was ill, I've been told I was demon possessed, I've been assaulted twice, I've been mocked, I've been given ECT...and it was all unnecessary. So it's like a real grief."	19
		16: "I had top surgery...even though it's what I want and it's good change, it's still change"	
2. Mismatch between needs as an autistic trans person and society	a) Gender as social behaviour	15: "I feel about gender roughly the same way that you might feel about like a big dessert at the end of a really good meal, in that the menu looks amazing and you should all have some if you like, there's so many delicious options, they look amazing, but I am good, I will just have a coffee, thank you very much."	15
		23: "It does hurt when someone calls me ... or perceives me as a man, I don't like that at all."	
	b) Struggle of being different	2: "It's only when you kind of get to secondary school and like the social expectations changed and then I really realised how different I was."	17
	c) Battle for support	18: "they [gender clinician] didn't really address me being autistic...it just felt a bit strange that they didn't notice it as part of my life I guess"	20
		6: "every service I'd ever had contact with had misunderstood me, and there was actually a fear that maybe the gender clinic will be the same"	

Discussion

In this IPA study of the experience of gender dysphoria, autistic participants described their experience of significant distress due to their gender identities not matching their bodies and struggle to articulate this experience, a need to understand their identities more broadly, and manage complex and intersecting needs. For some individuals, gender-related distress was increased by being autistic, with some participants feeling autism increased the intensity of dysphoria, while others described how features of autism allowed more freedom of gender expression. Participants faced difficulties in the social aspects of gender expression and societal norms around gender identity, experienced distress when not treated as their gender by others and due to being autistic and living in a world which is not always accepting of gender- and neuro-diversity. Participants experienced barriers in accessing healthcare for their gender needs.

All participants experienced distress due to a mismatch between their gender identity and sex assigned at birth and their bodies, as identified in previous qualitative work with autistic transgender individuals (Strang et al., 2018; Coleman-Smith et al., 2020; Strang et al., 2020b). The autistic people interviewed in this study generally experienced negative emotions, including depression and anger, which were related to gender dysphoria and similar to the emotions reported by the broader community of those who experience gender dysphoria (Cooper et al., 2020). Many participants struggled to put these complex feelings into words, and it may be that the social communication differences characteristic of autism (DSM-5; American Psychiatric Association, 2013), and higher rates of alexithymia (Kinnaird, Stewart & Tchanturia, 2019), increased the likelihood that their experiences were misinterpreted by clinicians. This may have led to some of the negative consultations with healthcare professionals described in the 'battle for support' theme.

Many of the participants in this study spent significant time and energy trying to understand their identities, a finding which aligns with qualitative research exploring the lived experience of autistic individuals (DePape & Lindsay, 2015). For participants in the current study, uncertainty about identity was often linked to gender, but also extended to sense of self more broadly, and for many there was a need to make sense of their identity as an autistic person. For some individuals, gender and autism identities were seen as essentialist, i.e. a fixed internal trait to be discovered, whereas for others, these identities were seen as socially constructed, i.e. malleable traits influenced by the social environment, mapping onto debates in the scientific literature (Walsh & Einstein, 2020). Whichever standpoint taken by individual participants, these findings suggest that some autistic people with gender dysphoria have longer and more complex journeys to come to understand their sense of self and identity, beyond gender identity alone.

The experience of distress due to a mismatch between assigned and affirmed gender was concurrent with a range of intersecting and competing needs. Transgender individuals are known to face high levels of discrimination and social isolation (Meyer, 2012). The participants interviewed in this study faced a wide range of additional stressors. These included individual stressors such as a conflict between autism and gender needs, other mental health needs, and contextual stressors such as experiences of abuse and trauma, which contributed to increased distress and discomfort in the self, in line with previous studies (Strang et al., 2020b; Coleman-Smith et al., 2020). Some individuals said that experiencing multiple stressors served to exacerbate their gender dysphoria, while others saw these additional stressors as being separate to the intensity of their gender dysphoria. The findings from this study suggest that autistic people may be more likely to have complex and multiple sources of distress which in some cases increased the intensity of their existing gender dysphoria.

We identified some aspects of gender dysphoria which interacted with autism. Autism was described as having a positive effect on the understanding of gender for some individuals, with being autistic facilitating awareness of gender identity. This is consistent with ideas of autistic people being resistant to social conditioning regarding gender (Walsh et al., 2018), and “gender defiance” in autistic people (Bejerot and Erikson, 2014). There were also descriptions of increased challenges at the intersection of autism and transgender identity, such as distress due to competing needs for routine versus undergoing a gender transition. Autistic people often have a preference for certainty, and in this study, some participants were distressed when they were uncertain about their identity. This fits with previous research which found confusion was a part of the experience of gender dysphoria in the general transgender population (Bailey, Ellis, & McNeil, 2014). Finally, sensory sensitivities characteristic of autism contributed to increased gender dysphoria e.g. trans men struggled with the sensory aspect of having periods alongside the feeling that their bodies did not fit their gender identities.

The *gender as social behaviour* theme highlighted that gender was expressed through and recognised by others as social behaviour and this could contribute to gender dysphoria for the autistic participants. The social differences characteristic of autism affected some participants’ understanding of how other people interpreted their gender expression. For some participants, less intuitive understanding of social conventions led to not identifying with gender norms; this was freeing for some, while others felt frustration when others expected them to conform to gender stereotypes. This fits with qualitative research with autistic women that found participants did not feel compelled to conform to gender norms (Kourti & MacLeod, 2019). The need expressed by participants to be seen as their gender identity by others clearly maps onto themes from previous

studies with the broader transgender population of experiencing distress due to being misgendered (McLemore, 2018).

The *struggle of being different* theme highlighted that many participants face minority stress due to not matching societal expectations because of both their autism and gender identities (Meyer, 2012; Botha & Frost, 2020). Participants were bullied and experienced adversity due to these differences. This suggests that autistic transgender individuals can face yet more social adversity than non-autistic transgender people. Also within this theme were feelings of shame about one's identity, likely linked to internalised stigma about their identities through these negative social experiences (Meyer, 2012; Botha & Frost, 2020).

The final theme focused on the ways in which participants advocated for themselves and managed to access healthcare to meet their varied needs despite additional barriers. Many participants felt let down by health services. Participants wanted their autism and gender identities to be acknowledged by health providers, without these becoming barriers to autism, mental health, or gender care. Participants identified a range of autism adaptations which would improve their experience of healthcare. These ranged from differences in practicalities about organising appointments, changes to the clinic environment, and changes in clinician communication. These adaptations are similar to those recommended for psychological therapy with autistic people (NICE, 2012; Cooper, Loades & Russell, 2018). The recommended adaptations are in line with recent findings that autistic transgender youth experience more executive functioning related barriers to accessing gender healthcare as compared to non-autistic transgender young people (Strang et al., 2021), and our qualitative findings suggest these difficulties are also experienced by autistic transgender adults.

A strength of this study was the focus on the lived experience of a group of participants who are frequently marginalised due to their identities as autistic and transgender (Meyer, 2012; Botha & Frost, 2020). We were able to recruit a range of participants from healthcare and community settings, with a range of gender journeys and stages of physical gender transition. We ensured that the analysis stayed close to the meaning of gender dysphoria to participants, emphasising their individual experiences. We carefully sampled adults who had a clinical autism diagnosis but who had broader experiences of distress around gender; this was a strength as it is relevant to many healthcare settings following WPATH standards of care (WPATH, 2012), including in the UK, where a diagnosis of gender dysphoria is needed to access gender affirmation interventions, but definitions of gender related diagnoses and services are rapidly changing. This was also a limitation, as we did not include individuals who would meet criteria for ICD-11 Gender Incongruence, but not DSM 5

gender dysphoria. A limitation was the larger sample size; while there are published IPA studies that include similar participant numbers (e.g. Smith, Spiers, Simpson & Nicholls, 2017), this meant that necessarily the analysis had to move on more quickly from the individual analysis of each case to analysing themes across all cases, as recommended by Smith, Flowers and Larkin (2009) for IPA studies with larger sample sizes. Future research should further investigate the inner experiences of transgender autistic people, with less focus on gender dysphoria, encapsulating a range of gender journeys and experiences, outside of diagnostic criteria. Moreover, research with a focus on the development of a sense of gender identity and both gender conforming and non-conforming behaviours in autistic children and young people is needed to understand gender identity development more broadly in this population.

In this study we identified core features of gender dysphoria which were experienced by autistic participants, such as distress due to a mismatch between assigned and affirmed gender, and when the individual was misgendered. There were also features of gender dysphoria which interacted with autism, such as a tension between a need for routine and a need to make a gender transition, and a sense of being less constrained by gender norms than non-autistic people may be. Participants needed to make sense of themselves in the context of being autistic and having negative social experiences, as well as to make sense of their gender identity. Discussing gender related questions with professionals was challenging for some participants, and some did not feel understood or supported. Clinicians working with this group should be aware of the differences in the autistic experience of gender dysphoria and make adaptations to their practice so that this group can access appropriate healthcare and support.

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Bailey, L., Ellis, S. J., & McNeil, J. (2014). Suicide risk in the UK trans population and the role of gender transition in decreasing suicidal ideation and suicide attempt. *The Mental Health Review*, 19(4), 209.
- Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and mental health*, 10(1), 20-34.
- Coleman-Smith, R. S., Smith, R., Milne, E., & Thompson, A. R. (2020). 'Conflict versus Congruence': A Qualitative Study Exploring the Experience of Gender Dysphoria for Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-15.
- Cooper, K., Loades, M. E., & Russell, A. (2018). Adapting psychological therapies for autism. *Research in autism spectrum disorders*, 45, 43-50.
- Cooper, K., Russell, A., Mandy, W., & Butler, C. (2020). The phenomenology of gender dysphoria in adults: A systematic review and meta-synthesis. *Clinical Psychology Review*, 101875.
- DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, 31(1), 60-71.
- Dhejne, C., Van Vlerken, R., Heylens, G., & Arcelus, J. (2016). Mental health and gender dysphoria: A review of the literature. *International Review of Psychiatry*, 28(1), 44-57.
- George, R., & Stokes, M. A. (2018). A quantitative analysis of mental health among sexual and gender minority groups in ASD. *Journal of Autism and Developmental Disorders*, 48(6), 2052-2063.
- Glidden, D., Bouman, W. P., Jones, B. A., & Arcelus, J. (2016). Gender dysphoria and autism spectrum disorder: A systematic review of the literature. *Sexual Medicine Reviews*, 4(1), 3-14.
- Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*, 23(7), 1871-1876.
- Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: a systematic review and meta-analysis. *European Psychiatry*, 55, 80-89.
- Kourti, M., & MacLeod, A. (2019). "I Don't Feel Like a Gender, I Feel Like Myself": Autistic Individuals Raised as Girls Exploring Gender Identity. *Autism in Adulthood*, 1(1), 52-59.
- Lai, M. C., Kasse, C., Besney, R., Bonato, S., Hull, L., Mandy, W., ... & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819-829.
- Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of psychiatric nursing*, 30(5), 575-580.
- MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders*, 64, 49-62.

- Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., ... & Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of autism and developmental disorders*, 49(8), 3387-3400.
- McLemore, K. A. (2018). A minority stress perspective on transgender individuals' experiences with misgendering. *Stigma and Health*, 3(1), 53-64.
- Meyer, I. H. (2015). Resilience in the study of minority stress and health of sexual and gender minorities. *Psychology of Sexual Orientation and Gender Diversity*, 2(3), 209.
- Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27, 883-887.
- Murphy, J., Prentice, F., Walsh, R., Catmur, C., & Bird, G. (2020). Autism and transgender identity: Implications for depression and anxiety. *Research in autism spectrum disorders*, 69, 101466.
- NICE. (2012). *Autism spectrum disorder in adults: diagnosis and management*. Retrieved from <https://www.nice.org.uk/guidance/CG142>
- Nobili, A., Glazebrook, C., & Arcelus, J. (2018). Quality of life of treatment-seeking transgender adults: A systematic review and meta-analysis. *Reviews in Endocrine and Metabolic Disorders*, 19(3), 199-220.
- Øien, R. A., Cicchetti, D. V., & Nordahl-Hansen, A. (2018). Gender dysphoria, sexuality and autism spectrum disorders: A systematic map review. *Journal of Autism and Developmental Disorders*, 48(12), 4028-4037.
- Smith, J. A., Flowers, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Smith, J. A., Spiers, J., Simpson, P., & Nicholls, A. R. (2017). The psychological challenges of living with an ileostomy: An interpretative phenomenological analysis. *Health Psychology*, 36(2), 143.
- Strang, J. F., Powers, M. D., Knauss, M., Sibarium, E., Leibowitz, S. F., Kenworthy, L., ... & Pervez, N. (2018). "They thought it was an obsession": Trajectories and perspectives of autistic transgender and gender-diverse adolescents. *Journal of autism and developmental disorders*, 48(12), 4039-4055.
- Strang, J. F., van der Miesen, A. I., Caplan, R., Hughes, C., daVanport, S., & Lai, M. C. (2020). Both sex- and gender-related factors should be considered in autism research and clinical practice. *Autism*, 24, 539-543.
- Strang, J.F., Knauss, M., van der Miesen, A.I.R., McGuire, J.K., Kenworthy, L., Caplan, R., ... & Anthony, L.G., (2020). A clinical program for transgender and gender-diverse autistic/neurodiverse adolescents developed through community-based participatory design. *Journal of Clinical Child and Adolescent Psychology*, 6, 1-16. DOI: 10.1080/15374416.2020.1731817
- Strang, J.F., Klomp, S.E., Caplan, R., Griffin, A.D., Anthony, L.G., Harris, M.C., ... van der Miesen, A.I.R. (2020). Community-based participatory design for research that impacts the lives of transgender and/or gender-diverse autistic and/or neurodiverse people. *Clinical Practice in Pediatric Psychology*, 7(4), 396-404. DOI: 10.1037/cpp0000310

- Strang, J. F., Anthony, L. G., Song, A., Lai, M. C., Knauss, M., Sadikova, E., ... & Kenworthy, L. (2021). In addition to stigma: cognitive and autism-related predictors of mental health in transgender adolescents. *Journal of Clinical Child & Adolescent Psychology*, 1-18.
- Strauss, P., Cook, A., Watson, V., Winter, S., Whitehouse, A., Albrecht, N., ... & Lin, A. (2021). Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from Trans Pathways. *Journal of Psychiatric Research*, 137, 360-367.
- Testa, R. J., Habarth, J., Peta, J., Balsam, K., & Bockting, W. (2015). Development of the gender minority stress and resilience measure. *Psychology of Sexual Orientation and Gender Diversity*, 2(1), 65.
- Thrower, E., Bretherton, I., Pang, K. C., Zajac, J. D., & Cheung, A. S. (2020). Prevalence of Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A Systematic Review. *Journal of Autism and Developmental Disorders*, 50(3), 695-706.
- Van Der Miesen, A. I., Hurley, H., & De Vries, A. L. (2016). Gender dysphoria and autism spectrum disorder: A narrative review. *International Review of Psychiatry*, 28(1), 70-80.
- Van Der Miesen, A.I.R., Hurley, H., Bal, A.M., & de Vries, A.L.C. (2018). Prevalence of the wish to be of the opposite gender in adolescents and adults with autism spectrum disorder. *Archives of Sexual Behavior*, 47, 2307-2317. DOI: 10.1007/s10508-018-1218-3 8.
- Walsh, R., & Einstein, G. (2020). Transgender embodiment: a feminist, situated neuroscience perspective. *INSEP—Journal of the International Network for Sexual Ethics & Politics*, 8.
- Walsh, R. J., Krabbendam, L., Dewinter, J., & Begeer, S. (2018). Brief report: Gender identity differences in autistic adults: Associations with perceptual and socio-cognitive profiles. *Journal of Autism and Developmental Disorders*, 48(12), 4070-4078.
- Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., ... & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature communications*, 11(1), 1-12.
- World Professional Association for Transgender Health. (2012). *Standards of Care for the Health of Transsexual, Transgender, and Gender-Conforming People* [7th Version]. <https://www.wpath.org/publications/soc>